Vermont & its Citizens with Developmental Disabilities
A Comprehensive Review and Analysis

This is the narrative section of the State Plan Amendment that VTDDC filed with the federal Administration on Developmental Disabilities on August 15, 2009. It describes Vermont and then focuses in on what we know about people with disabilities here; the supports, resources and services available to them; and participation in community life.

A. Prevalence of Developmental Disabilities in the State

There are an estimated 13,145 people with developmental disabilities living in Vermont. This figure is based prevalence rate used by the Vermont Division of Disability and Aging Services in its data and reporting: 1.5% with developmental disabilities PLUS .6% with pervasive developmental disability (i.e. autism.) applied to 2007 U.S. Census estimates.

B. Environmental Factors Affecting Services.

Political: Vermont ranks 49th in the nation in population & 45th in size. It's the most rural state, with 38% of its 625,000 inhabitants living in urban areas. The largest metropolitan area rings Burlington, with 4 urban centers & approximately one-quarter of the population; the next largest city, Rutland, only 17,000. Since it was a republic, before it became the 14th state, VT has had a tradition of political independence, with government based on the town unit. There are 251 communities, including 237 towns and 9 cities. There is no tradition of county elected government. There is now an overlay of regional state government, including 12 Agency of Human Service district offices covering 14 counties.

Developmental services are funded by the State, and accessed through nonprofits at the regional level that are not directly linked with the regional state agencies. The educational system also remains grounded in town-run elementary schools, overlaid by a state-developed system of 60 supervisory unions. This structure has been a barrier to an equitable distribution of quality, specialized special education services state-wide, as well as uniform standards and data collection, for example restrictive behavioral interventions.

VT has a citizen-run legislature composed of 30 senators and 150 representatives who are elected for 2 year terms, and meet for two-year sessions from January to May. Legislators welcome direct advocacy by consumers, including home phone calls. In 2008 Vermonters reelected a Republican governor for a 3rd term, & increased the Democratic supra-majorities in both Houses. The Legislature's FY2010 Budget Bill differed from the Governor's proposal, with less cuts & slight tax increases. The Governor vetoed the Budget – a first in VT history. It was overridden by a Democratic-Progressive coalition (along with a same sex marriage bill.) One U.S. Senator & VT's Representative are Democrats; the other Senator is Independent.

Quality of Life. Vermont is known for its scenic beauty, its winter snows and skiing, and its safety. Also its tolerance, as evidenced by passage of the first U.S. same sex marriage law. Its environmental planning laws resulted in less real estate speculation, & Vermont is weathering the "Great Recession" a bit better.

In 2005 VT had the lowest % of motor vehicle deaths & lowest violent crime rate in the nation. It ranked 2nd in United Health Foundation's Health Rankings, cited for ready access to prenatal care, a low infant mortality rate, and a low premature death rate. Some of VT's

rankings went up, however, due to downward trends nationally. Between 1990 and 2005 the high school graduation rate dipped from 82.7% to 78.6%. At the same time, 90% of incarcerated youth are high school dropouts, and it is estimated that 60% are former special education students.

About 10.8% (60,000) Vermonters were without health insurance. Attempts to pass more universal access were stymied by threat of a gubernatorial veto, and more modest proposals were passed in 2006 and 2007 to reach more working Vermonters. VT does have virtually universal coverage for children through the Dr. Dynasaur Medicaid program, which can supplement private insurance, and it has maximized Katie Beckett waiver coverage to over-income families of children with developmental disabilities.

Adults with developmental disabilities most often live with their parents, or in developmental homes outside of population centers, impeding easy access to recreation and other social activities. Public transportation is unavailable in most parts of VT. Its few minorities tend to reside in its small cities, & its growing refugee population requires outreach efforts to determine needs. Although it has a low incarceration rate, VT has also seen the highest growth in prison population in US – double in 10 years, with concerns that many inmates were special education students &/or have developmental disabilities.

Economic: Decreases in state revenues in 2008-9 resulted in cuts to state programs, including developmental services. Unemployment is on the rise, including state workers. VT was also hard hit by high energy costs. In 2007 VT's per capita income (36.670) slipped below the national average. Its unemployment rate dropped from best in US in 2005 to 20th in 7/08. Tourism employs 39% of the service sector -- the fastest growing sector VT's economy. Dairying is 80% of total farm income; electrical manufacture 33% of industrial income. Strict environmental regulation is cited as a barrier, yet VT continues to attract & grow business.

VT ranks 4th in US for working environment, & is known for its educated workforce, ranking 9th in % of the adult population with high school (80.4%) & 10th with college degree (29.4 It has the 7th highest t tax burden as % of personal income.) The 2004 NCPPHC report rated VT "F" in affordability of higher education due to lack of state investment. A number of young Vermonters leave the state for less costly college education, & don't return. The Governor spoke out on the need to tap every source to address VT's labor shortage in VT, while people with developmental disabilities remain underused as employees. (See III.C.2.)

VT now has an estimated 2000 undocumented farm workers from Mexico & a number of exchange programs that bring student workers to its ski resorts from Peru & other nations. Livable wages are a barrier; in 2007 a single person needed $14.54 per hour; up to 55% of households with children do not earn $17.87-26.10 needed.

Another barrier is affordable housing: VT's rental vacancy rate of 4.9% is 2nd in US; homeownership vacancy rate is 1%, with estimated shortage of 21,000 rental housing units. 54% of renters pay more than 30% of income for rent, & 65% of households do not earn the median income required to buy a home. The situation is compounded when heating oil and & gasoline rises – essentials in a northern rural state.

Legal context: VT's Olmstead Commission started in 2002 and issued its report in Dec. 2005, with a comprehensive inventory of services & supports for Vermonters, & cost projections for full community participation. However, there was no implementation plan, & no steps taken since its release.

VT ranked 1st in the nation in United Cerebral Palsy's 2009 Full Inclusion Report. It closed Brandon Training School, its only institution for those with developmental disabilities, in 1993, & its last sheltered workshop in 2002. Concerns include adult protective services, with only 5 investigators state-wide, and limited safeguards for the majority of those with waivers living with contracted home providers in developmental homes. VT also receives high scores for inclusion of children at school. However, it does not offer a continuum of placements and has just begun to address the needs of children with autism on a state-wide basis. There is also increasing concern about the limited ability of the Dept. of Education to address the use of restrictive behavioral interventions in schools, outside the system of mandated reporting that covers the home and other settings like child care centers.

VT took note of successful federal litigation on EPSDT services; however after advocacy efforts by the Disability Law Project only $800,000 of $2 million allocated for limited EPSDT case management & therapies reached children, youth and families (1654 eligible.) DLP was unsuccessful in bringing a class action lawsuit against the State to stop cuts in Medicaid-funded dentures, chiropractic care and elective surgery.

Through legal actions VT P&A achieved more humane approaches to prisoners who self-injure, & law enforcement transport practices during emergency calls from families & people with autism, mental health & other disabilities. DLP was also successful in gaining a TRO so that a young man could "walk with his class" at graduation, and continue on in special education.

C. The State Service Systems:

System Overview: VT's Developmental Disabilities Act bases eligibility on label of mental retardation (IQ below 71) or PDD, with adaptive skills component. The Act provides for a System of Care Plan [SOCP] to set "funding priorities" for 3-year periods (currently 7/1/07-6/30/10) People who are eligible do not get funded for home & community based waivers unless they meet one of the System Of Care Plan's priorities.

Since 2001 priorities are based on emergency situations - homeless; danger to self or others; loss of primary caregiver, with a separately funded priority for employment supports for high school graduates with a job in place. Priorities are driven by funding, & have been adjusted yearly with little process to fit within the DS budget. Since 2001 any changes have restricted priorities: elimination children's waivers; flexible goods funding; & raising the age for employment supports at high school completion.

The system is operated through 11 regional nonprofits, called Designated Agencies [DAs], that are recertified every 4 years. DAs decide eligibility for new applicants, set funding levels, create individualized budgets & also provide services to most people. Funding packages over $4,000 are approved by a State Equity Committee. An additional 6 agencies called Specialized Service Agencies provide more limited range of functions.

DAs are also the access point for Flexible Family Funding [FFF-now Medicaid funded] -- the cap dropped from $1300 to $1000 (provided on a sliding fee basis to 926 families with members who are eligible but do not meet waiver priorities. The Pacific Health Group analyzed the sustainability of this system in 2004 & 2007 studies; it cited high staff turnover; inefficiency of service silos; and the need for stable funding increases as significant pressures in coming years. The system is based on individual budgets that are supposed to follow Individual Service Agreements [ISA]. However, recent rollbacks are impacting individualized services.

Services & Self-Management: 3545 people with developmental disabilities are served, about 25% of estimated eligible. 2270 through home and community-based waivers (339 children & 1931 adults), & 972 through Flexible Family Funding (855 children & 117 adults). Average 2008 waiver is $53,798 - 5th in US. Its 2006 rank was 14th in fiscal effort: $5.72 per $1000 income, down from 10th. Its use rate is 7th in US (215)

Waivers are grounded in individualized budgets that specify limited funded areas -- include employment, community & home supports; service coordination, respite etc. Pacific Health Group's 2007 VT Study recommended more budget flexibility to increase cost-savings and satisfaction.

VT ranks 1st in employment, with 39% (885 people) supported to work; however they average 10 hours per week, with 33% wanting more hours. 1367 people receive community supports; 407 people receive both. Of 1402 receiving home supports, 77% (1083) live with home providers; 14% (193) are in supervised living. About 800 live with family, 25% with parents over 60. Individual budgets include local and state crisis intervention items to contribute to infrastructure.

2009 cuts resulted in direct hits to people's budget. Goods were eliminated; & people were moved into wrap services & congregate day services. DAs consider limited requests for funding increases or shifts in areas funded; funding requests over $4000 are directed to a state-level equity committee. Self & Family-Management: Individuals and families may opt to self-manage services. Use of self-management has been flat; in 2007 there were 51 individuals and families self-managing. Funding is channeled through an independent support organization. Among the disincentives to self-management are service coordination rate caps, and stringent oversight of billing and paperwork. Also, the same funded areas of support are used in self-managed budgets, so the self-management option does not offer additional flexibility about what can be funded.

***Family & Children's Services*:** 2009's Annual DS report stated "Supporting people living with their own families continues to be the most cost effective method of support." Since 1996 support increased from 30% to 44% of those served. The Flexible Family Funding program doubled in 8 years. 13% of the DS budget is spent on family support vs. 5% nationally. VT ranks 9th in support per family - 1of 12 states spending over $10,000. NOTE: Average includes individual community & employment supports to people living at home, but not personal care services.

Children: At 9.4%, VT ranks 3rd in the US in % of people 5 to 20 identified with a disability. VT prides itself on including children in local schools, ranking 1st in the US in percentage

(82%) of special education students in regular classrooms at least 80% of the time. (National average is 48%) At the same time it ranks 2nd highest for children in private residential facilities – most out of state – due to the lack of a continuum of placements. Another trend is earlier graduation based on credits, not meeting IEP goals.

Waivers for children with developmental disabilities were suspended, then eliminated in 2001; 372 children & their families are still funded, with 140 living outside the home (most over 18). Two alternative funding resources are available: (1) 795 families receive Flexible Family Funding -reduced to $1000per year. (2) 1696 families receive Medicaid entitlement services (93 High Tech Home Care, 1654 EPSDT Personal Care & 51 both). Average age for PCS is 12; average hours per week are 20 (down from 25 in 2006). VT's Division of Developmental Services now decides eligibility. There are no case management dollars & wages are low, so few agencies offer services; families self-manage & 25% of hours go unused. Although there are treatment plans, no professionals recruit, train & supervise staff. Only $800,000 of $2 million allocated for FY09 by the legislature is being used to address gaps in EPSDT direct services.

Inclusion & Self-determination Trends: VT leads the US, with 100% of people living in placements with 6 or less, & lowest average 1:2. United Cerebral Palsy's 2009 Full Inclusion Report ranked VT 1st in US. 1367 Vermonters receive community supports & participate in National Core Indicators; surveys report a broad range of activities.

VT's rural nature & home provider model can limit opportunities: many are dependent on family or home providers to get out into the community. 46% voiced a need for more community support hours; 41% for friends; & 35% don't make choices about community activities. DDS has identified increased choice in living options as a need. Most were satisfied with housing but indicated limited choices: 91% liked where they lived & 86% liked who they lived with; however 51% said others chose the place & 39% said others decide when friends or family can visit. While many had choices about employment, 58% did not choose job coaches & 51% did not choose their job. Overall, 78% reported enough control over their lives; but 44% said there are more choices they could be making. 69% reported not choosing case managers; 50% not being told about budgets; & 70% not told about appeal rights. While 86% see themselves as self-advocates, 40% want more involvement.

Recent policy changes and cuts are eroding choice & self-determination, with loss of goods; more people in wrap services controlled by home providers on contract; & people moved into congregate day services. Self-Advocacy: VT's vibrant Green Mountain Self-Advocates has over 1000 members & network of 17 local groups, with new high school chapters & groups for working people. It receives an unrestricted State grant & funding for a Coordinator & has also received grants to develop trainings & materials by self-advocates for self-advocates. Materials it distributes nation-wide include "Your Bill of Rights" video; "Getting On Board & Making a Difference" manual; & "Stay Safe and Know Your Legal Rights" training.

Social Services Delivery System & Medicaid**:** VT's Agency of Human Services has been reconfigured from 7 departments into 5, with a new Department of Aging and Independent Living that includes the Division of Developmental Services & Vocational Rehabilitation. (Dept. of Mental Health was reinstated in 2007.) An intent of the reorganization was to be a consumer-oriented model of service; recent surveys demonstrated that this has yet to be

achieved. One of the most promising parts of the reorganization was the creation of 12 field service offices to assist consumers to bridge services across departments at the local level. Although 12 field service directors were hired, the state did not provide sufficient funding for peer navigator positions that were intended to provide direct assistance to people and families. VT launched the model through a 360 grant awarded to AHS with contract to VT's UCED CDCI, directed at assisting parents with disabilities. Peer navigators are working up to 15 hours per week.

MEDICAID GLOBAL COMMITTMENT: VT ranks 1st in maximizing Medicaid funding with state dollars. It was the first state in the nation to negotiate a state-wide block grant-type Medicaid waiver with CMS; the only exclusion was a recent 1115 waiver for long term care. The "Commitment" sets a 5 year cap on federal Medicaid reimbursement. Advocate concern included loss of entitlement to core Medicaid services. State officials focused on looming Medicaid deficit and assured advocates that the cap was set high enough. As cited by PHG in its 2007 Study VT has not taken advantage of flexibility offered; it continues to provide services in silos and to restrict individual budgets in ways that are not individual or family-centered. VT may be hitting the cap already. Challenges include extending the range of EPSDT services to include case management & therapies.

Interagency Collaboration: There has been a history of tension between the Department of Education [DOE] and the Agency of Human Services [AHS] that is fueled primarily by funding limitations, but also by labels that have stifled more creative approaches to address the needs of those they both serve. Among the initiatives to jointly address individual and systems concern was to use the legislatively mandated Local Interagency Teams (LIT) in the 12 AHS regions that bring together the school and designated staff to address the needs of youth with severe emotional disturbance. A new interagency agreement has been signed that will extend the system to all IEP students. Of concern is whether there will be the necessary commitment of resources for the ambitious expansion of the role of the LIT Team, including adding a family consumer representative. The agreement also outlines with some specificity how the schools and AHS will collaborate for successful transition planning, including the involvement of Vocational Rehabilitation.

VT has in place several successful models for service coordination across agencies. The early intervention program FIT (Family, Infant & Toddler Project) uses a service coordination model that has had success in assisting families to tap medical, educational, and developmental, as well as community services. Grant funded peer navigators employed by nonprofits are sited at each AHS region's Field Service Office and have been actively assisting families, including parents with disabilities, to navigate across agencies. Most recently following legislation DOE & AHS have worked jointly on an Autism Plan and are revising interagency agreements to serve that population; families still report little if any integration across education and social services, and between the developmental and mental health service systems. This is compounded by the lack of EPSDT case management and waiver funding for children.

D. Community Services and Opportunities. [See outline of services and needs above.]
Vermont's developmental services budget was cut to $131 million during FY09 (includes federal Medicaid - exclusive of Education, Transportation, Vocational Rehabilitation, etc.) Most funding is for home & community-based waivers for individuals. FY08 was the end of a 3 year agreement that stabilized funding increases to DA's to address staff turnover & rising expenses per Pacific Health Group's 2004 Sustainability Study. Its follow-up 2007 study recommended 8% annual increase to maintain existing caseload. Instead, in FY09 the increase was rolled back to .125%; a 3.5% cut in December resulted in uneven staff hits & loss of services to individuals across the state. Despite legislative changes the FY10 budget funds less than half the graduates eligible & the waiting list is growing. PHG also recommended moving from VT's silos to individual & family-centered services to achieve cost savings and increased satisfaction. Cost projection highlights from the Dec. 2005 Olmstead Commission Report: $600,000 annually for information & referral navigators; $600,000 for residences for people who are deaf/hard of hearing; $935,000 for wait list (11) for adaptive vans; $2.6-$8.1 million for Elders & Persons with Disabilities Transportation Program; $2.38 million for employment support for 1000; $520,000 for summer youth & work experience programs; AT specialists: $1.65 million to fund .5 FTE in each school district & $600,000 in each AHS region; $600,000 to support 70 parents with disabilities; $50,000 for a state-level DS Ombudsperson; $2 million annually to eliminate children's wait (72) children & $1.1 million to serve 40 children per year; $1.84 million to support 65 individuals at high school transition; $3.13 million to support 7.5% increase for workforce; $5 million to fully support emergency caseload; & fund health care & other supports & services received in ICF(MRs)& through Waivers.

E. Waiting List	Waiting List Name	Number
List: 1	Applicant List	241
List: 2	Waiting List	36

VT's Developmental Disabilities Act sets up a 2 step process for services: 1. Meet eligibility i.e. label of mental retardation (IQ below 71) or PDD plus adaptive skill deficit AND 2. Meet a "funding priority" in VT's System of Care Plan. The SOCP sets "funding priorities" for 3-year periods; key priorities for HCBS since 2001 are based on emergencies and remain unchanged in latest FY08-10 SOCP (homeless; danger to safety; & about to be institutionalized; death or loss of a caregiver; with limited funds for high school graduates with jobs & for parents with disabilities). The priorities continue the increased age for transition employment supports. 2001 closure of caseload to new children continues to divert demand to Medicaid's EPSDT personal care program (with no case management), & Children with Special Health Needs' limited respite funding. Although VT regulations call for only one WAITING LIST of people eligible for services who do not meet a SCOP funding priority, the State has divided the list into 2:

WAITING LIST and APPLICANT LIST.
Regional non-profit designated provider agencies are the gateway to services and keeper of the lists. Agencies use a screening sheet, not an application. Written decisions appear to be rare for those eligible who do not meet a priority, even when they are added to the applicant list. The intake process discourages potential applications & undercounts those eligible who are not assisted to go further than an initial screening call.

The "**APPLICANT LIST"** includes all people eligible for services based on their disability but who do NOT MEET the restricted Funding Priorities in the SOCP (outlined above). Since SOCP priorities have not changed people stay on this list indefinitely-- 241 in FY08, compared with 213 in FY07; 169 in FY06; & 106 in FY03. The total cost of addressing the Applicant List would exceed $10 million. The 43% jump in the "Applicant List" in 2 years underscores the inadequacy of funding to meet needs even using a narrow definition.

"WAITING LIST". It includes people who are eligible for services & MEET the restricted State System of Care Plan Funding Priorities waiting for funds to be available – typically families waiting for Flexible Family Funding. The State calculates costs to fund based on $1000 per family + administration i.e. approx $40,000 for 36 families currently on the list. (Compare 31 in FY07; 9 in FY06).

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